# Research Paper

# Asthma in Middle Schools: What Students Have to Say About Their Asthma

Guadalupe X. Ayala, Delesha Miller, Edwina Zagami, Connie Riddle, Stephanie Willis, Donna King

ABSTRACT: Preadolescence involves cognitive, social, and physiological changes along with changes in the child's environment. During this developmental stage, young adolescents are transitioning into middle school, forming a larger social network, and managing parental expectations for assuming more responsibility for self-care. The impact of these developmental changes on asthma management is not well understood. The purpose of this study was to better understand asthma and asthma amanagement from the perspective of middle school students. A partnership was formed between the university researcher, several school nurses, and a representative of the health department, through the Orange County Asthma Coalition. Funds were secured from the American Lung Association. School nurses helped to identify and recruit 50 middle school students with asthma to participate in focus groups. The focus group discussions centered on asthma management with implications for intervention development. Analyses sought to identify developmental issues that affect management. Results indicated that the transition to middle school represents a challenge to managing asthma. As compared with the elementary school environment, support structures are broader and more diffuse, physical education is more demanding, and peer pressure is greater. Nevertheless, the desire for greater autonomy and independence in self-care was strong, particularly among eighth graders. Most interventions are designed for either children or adults, without recognizing the important developmental changes that are occurring in preadolescents with implications for asthma management. A school-based intervention in middle school may help students with asthma transition to greater autonomy of care, while easing transition in other domains of life. (J Sch Health. 2006;76(6):208-214)

#### INTRODUCTION

The transition to adolescence involves stronger peer affiliation, changes in self-identity, a larger social network, more settings in which activities take place (work, school, peer homes), and a greater likelihood of engaging in risk behaviors that exacerbate asthma symptoms. 1-2 Asthma may inhibit activities as a result of social isolation or restrictions imposed by health care providers or parents, affecting how well the adolescent copes with the illness.3-6 From a social ecological perspective, chronic illness management is influenced by intrapersonal (self-efficacy, outcome expectations, cultural beliefs), interpersonal (parent-child relationship, doctor-patient relationship), and societal factors (income, education, access to care).7-8 Successful adherence may be particularly problematic among young adolescents due to their short-term outlook and a developing ability to engage in abstract problem solving. Children may be more adherent with parental involvement, although this

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may be mediated by the type of involvement (more adherence among adolescents if parents foster independence).<sup>9</sup> As a result, the National Institutes of Health recommends that providers, parents, and adolescents work collaboratively to develop an asthma management plan, thereby fostering greater care autonomy.<sup>10-11</sup>

#### **Present Study**

This study gathered information from middle school students on factors that influence asthma management. We sought to identify developmental differences between sixth, seventh, and eighth graders and changes in management with the transition into middle school. Over 3 months, students from 2 middle schools participated in focus groups to inform the development of an intervention.

# **METHODS**

# **Setting and Partnerships**

This study was conceived over several meetings with members of the Orange County (OC) Asthma Coalition in North Carolina. The coalition includes school nurses, physicians, health department personnel, tobacco control specialists, and public health researchers. This study represents the formative research phase of an intervention to improve asthma management among middle school students. All study protocols were approved by the OC School Board and the Institutional Review Board (IRB) at the University of North Carolina at Chapel Hill.

### **Recruitment of Schools and Participants**

Two middle schools were selected by the coalition members based on the diversity of the student population (30% nonwhite, 12% on free and reduced lunch program), asthma prevalence rates (approximately 10%), and strong school nurse interest. These schools serve a suburban student population.

Several factors influenced selection of our student recruitment process: (1) we did not have access to school records to identify students with asthma and (2) we received permission from the IRB to obtain passive informed consent from parents. This led us to conduct a multistage recruitment process using passive and active methods.<sup>12</sup> To provide parents the opportunity to decline their child's participation, in early spring 2004, the school nurse mailed a study information letter to parents of students with asthma as reported on school health records (n = 124). Twenty-six parents (21%) declined their child's participation, and 5 of these indicated that their child no longer had asthma. No information is available on these families given the lack of access to school records.

Two weeks later, 2 research assistants went to the school during the student's lunch hour and distributed study information fliers. Interested students with asthma were instructed to write their contact information on a sign-up sheet (n = 66). The school nurse then verified the asthma diagnosis using the school health records, and a research assistant verified that the parent had not refused their child's participation. All 66 students who signed up for the focus groups were verified as having asthma based on the school health records, and only 1 interested student had a parent who declined his participation. Our final sample consisted of 50 students (76%) who attended the first focus group and signed an assent form (see Table 1).

# **Data Collection**

Seven weekly focus-group sessions were held with each grade level at each school, yielding 42 completed focus groups. The topics included asthma management and barriers, developmental issues, support for asthma care, intervention preferences, critique of existing materials, and logo and project name brainstorming. All focus groups were held during the students' 35-minute lunch period and were grade specific, given school lunch schedules. We minimized attrition over the study period by making reminder calls the night before each focus group, distributing student passes on the day of the groups, and providing lunch during the groups.

The focus groups were facilitated by a doctoral student and a master's student from the University of North Carolina at Chapel Hill. The principal investigator attended 4 of the 42 sessions to observe the facilitators, model how to ask open-ended questions, and provide feedback on their facilitation skills. Group discussions were tape-recorded and transcribed verbatim for data analysis. Before the first focus group, the students completed a short survey that included demographic questions and asthma management behaviors. One question assessed the students perceived control of their asthma from 0 = no control to 100 = complete control. Following the last focus group, the students completed a second survey on intervention preferences. Students received 2 gift certificates of \$7.00 each for completing the 2 surveys.

#### **Data Analysis**

A combined inductive/deductive approach guided the focus-group data analysis. 13-14 The first and second authors

read a representative focus-group transcript, identified themes to represent the data, met for consensus on the themes, and refined the thematic codebook. This process was completed with 2 additional transcripts to refine the codebook. Using the final codebook, all transcripts were coded independently by both readers and then compared to reach 100% consensus. The transcripts and codes were

Table 1

Demographic and Asthma-Related

Characteristics of Focus-Group Participants

Mean age (SD) Percent female Ethnicity African American Caucasian/White Others Grade in school Sixth grade Eighth grade Asthma characteristics Mean perceived level of asthma control (0-100) Medication regimen Percentage of students on controller medication Percentage of students on long-acting beta-agonist Have access to medication Have a peak flow meter at home Have a spacer to deliver medication Have an asthma diary Median number of people in  Percent female  12.46 (1.05) 56% (28) Ethnicity 48% (24) 60 60 60 60 60 60 60 60 60 60 60 60 60		Mean (SD) or % (n)
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Range of asthma 0-10 people	Range of asthma	0-10 people
support network size	support network size	
Members in asthma	Members in asthma	
support network	• •	
Mother/stepmother 82% (41)		
Father/stepfather 36% (18)	Father/stepfather	36% (18)
Siblings 14% (7)	Siblings	14% (7)
Grandparents 12% (6)		
Other family members 18% (9)	Other family members	
Doctors 10% (5)	Doctors	10% (5)
Friends 4% (2)		` ` .
School nurse 2% (1)	School nurse	2% (1)

N = 50

imported into NVIVO and categorized by grade level. The final step involved the identification of subthemes, which are presented below with representative quotes. Data from the surveys were analyzed in SPSS v11.0 (SPSS Inc., Chicago, IL). Descriptive statistics (means and standard deviations [SDs]) were used to characterize the sample.

#### RESULTS

# **Asthma Management Resources: Quantitative Results**

Based on self-reported medication use, half of the students were either on a controller medication (42%) or on a long-acting beta-agonist (4%). However, students reported minimal access to asthma management resources (Table 1). Half of the students reported access to a peak flow meter (52%) and spacer (58%); 10% and 12% reported use of an asthma diary and asthma action plan, respectively. The mean level of perceived asthma control was 72.80 (SD = 24.44, range: 5 to 97), suggesting that the students felt their asthma was mostly under control. The predominant interpersonal resource was mothers (82%), followed by fathers (36%), with a median of 2 sources of support (range: 0 to 10 people).

# Asthma Management Perceptions and Behaviors: Oualitative Results

We identified 4 themes: barriers and contextual influences, developmental issues, illness representation, and appealing to youth. Given our interest in developmental differences, we describe consistent results across all grade levels followed by differences between the 3 grade levels.

Theme 1: Barriers and Contextual Influences. Barriers to Successful Management. Students cited several global reasons why youths are poor managers. Across all 3 grade levels, students reported that managing asthma was "time consuming" and "annoying." Sixth graders reported being scared about asthma and not wanting to be different or teased by peers. Seventh and eighth graders reported that management behaviors were "not needed" because they had outgrown their asthma or it was not severe enough to warrant attention.

Barriers to medication use were influenced by attributes of the medicines themselves and students' personal beliefs about asthma medicines. The students noted that asthma medicines taste bad, are complicated to use, and are costly. All students believed that taking medicine was inconvenient, undesirable, or unnecessary. Common reasons for poor medication adherence included forgetting to take medicine to school or to a friend's house (all grades), losing inhalers, and being lazy or irresponsible (seventh and eighth). Other grade differences emerged. Sixth graders used medicine to help them with breathing emergencies or to achieve specific outcomes, "I can play sports more when I take my medicine." Eighth graders were the only group to recognize the preventive properties of asthma medicine, for example, "I don't have attacks when I take my medicine."

With respect to symptom monitoring, most students believed that a peak flow meter was only used with "bad" asthma or did not find the reading helpful for decision making because it did not match other common signs and symptoms. Sixth graders also believed that a peak flow meter was only used when exposed to asthma trig-

gers, while seventh and eighth graders did not believe it was an essential management component or had outgrown its usefulness. This latter finding may be due to students experiencing fewer symptoms as they get older.

In terms of environmental trigger control, the students were quite knowledgeable about triggers that cause asthma episodes, yet they did not avoid known triggers like cats and dogs because of the benefits associated with having a pet. Students also believed that exposure to some triggers, like cigarette smoke, was unavoidable.

Contextual Influences. Each environment presented unique challenges to managing asthma. Students reported that at school, teachers and coaches often accused students of faking asthma attacks, inhibiting them from reporting attacks. Among peers, students reported that it was difficult to turn down a friend's offer to play basketball when the pollen count was high. In all contexts, the most commonly cited management strategy was to alter their activity level. This involved knowing one's physical limits and sitting down or relaxing until the episode subsided. Consistent with developmental theory, eighth graders identified more locations where asthma episodes occur when compared with seventh graders.

Theme 2: Developmental Issues. Three subthemes emerged from the analysis on developmental issues: changes in asthma symptoms, changes in autonomy and parent involvement, and contextual changes.

Changes in Asthma Symptoms. Students across all grade levels believed that they were experiencing less asthma symptoms as they got older. Students in sixth and seventh grades believed that using less medicine was a sign that they were outgrowing their asthma.

Changes in Autonomy and Parent Involvement. Students felt that they were gaining more autonomy for asthma management from parents. Students in all grades stated that they had more control over medicine in middle school than they did in elementary school, yet parents maintained primary responsibility for environmental trigger control. This was especially evident from the focus groups with seventh and eighth graders. Some parents of seventh graders appeared to take an active role in transferring responsibility of medication management by teaching their children how to use inhalers. One seventh grader indicated a positive outcome of this autonomy: "It doesn't feel like I'm a hopeless." Eighth graders referred to this as being treated like an adult. One eighth grader noted that, "Yeah, it has gotten less and less ... like they sort of make it your responsibility, when it sort of used to be theirs when you were little."

Despite this transition toward greater autonomy, continued parental and other family involvement in asthma management was acknowledged by seventh and eighth graders. For example, reminding them to bring their inhaler to school or to take their medicines before bed. This was particularly true for students who were not managing their asthma well: "My mom got more and more suspicious about it, because she kind of got mad at me because I won't tell her, but I'm like, you know, because I didn't really face it until I can't breathe at all, so I didn't do anything." This continued involvement was met with anger and frustration among seventh and eighth graders, with students noting the negative effects of "nagging" such as lying about medication use.

Contextual Changes. Two contextual changes occurred as students transitioned from elementary to middle school. Students in sixth grade noted that having multiple teachers posed problems for asthma management. One sixth grader said that, "It was like through kindergarten and elementary, it was a lot easier to manage it because, you know, the school's so small and everything, and basically you knew everybody, and when you had an attack, people would actually like worry about you. Here in this school, it's so big that nobody, everybody could care less." Sixth and seventh grade students also stated that the change in physical education requirements made it more difficult to manage asthma at school. These students said that "more laps" in middle school caused them to experience more breathing problems.

Theme 3: Illness Representations. Illness representations or how people view themselves and their disease varied across grade levels, with 3 subthemes emerging from

the data: characteristics of good and poor asthma managers, perceived severity of asthma, and media portrayals. 15

Good and Poor Managers. Words used to describe good and poor managers are presented in Table 2. Students ascribed positive attributes to good managers and negative attributes to poor managers. Sixth graders referred to poor managers as soft-spoken people who try to hide their asthma and throw away their medicine, whereas seventh and eighth graders referred to poor managers as unhappy or stressed, a loner, and have nerdy or dorky friends. One seventh grader noted that "you might not feel comfortable around him 'cause he's always disappearing." In addition, seventh and eighth graders thought that good managers engaged in more inactive pastimes such as watching TV and movies.

Perceived Asthma Severity. Perceptions of asthma severity were consistent across all 3 grade levels. Sixth graders believed asthma was not as severe as attention

Table 2

Descriptors of Good and Poor Asthma Managers

	Sixth Grade	Seventh Grade	Eighth Grade		
Good Managers	Cool	Lucky	Нарру		
-	Popular	Normal	Normal		
	Plays sports	Popular	Regular kid		
	Living	Laid-back	Smart		
	Can breathe	Nice	Friendly		
	Cutie	Likable	Hangs out with friends		
	Has lots of girlfriends	Jock	Watches TV and movies		
	Smart	Nice smile	Plays sports		
	Big	Cool friends	Has cool friends (football players)		
	Tall	Plays sports	Popular		
	Nerd	Talks on phone	•		
		Watches TV and			
		plays video games			
		Surfs the Internet and			
		uses instant messenger			
		Takes his medicine			
Poor Managers	Soft-spoken	Bad asthma	Not happy		
Ŭ	Cannot talk	Stressed out	Freaky		
	Not controlled	Not popular	Sick and tired of asthma		
	Does not like the	Not controlled	Loner		
	taste of medicine				
	Hides or throws away asthma medicine	Disappearing to take medications	Not smart		
		Only fits in with nerdy	Quiet		
		and dorky friends			
		Plays chess	Does homework		
		Practices math	Watches TV		
		Tradition main	Stays home		
			In poor health		
			Cannot participate		
			Bad grades		
			Friends tease		
			Goes to the nurse's stat		
			at least once a week		

deficit hyperactivity disorder (ADHD) or diabetes because you "can't do anything about it" and "you only have to think about it when you're having problems." One sixth grader aptly noted that "Asthma really isn't a life consuming thing that you actually think about all the time. You only think about it when it actually affects you." Similarly, seventh graders thought that asthma was less severe than diabetes because sugar is in everything but asthma is only situation specific. Eighth graders demonstrated the most complex thinking about the issue stating that in general, asthma is not as severe as diabetes because "you can still achieve a lot of stuff," but if you have really bad asthma, then it can be as severe as diabetes. Nevertheless, 1 eighth grader commented that it was better to attribute limitations in activities to things other than asthma: "I be on a team and lose, and it's like oh well. Because sometimes you can't give your full effort because your asthma defects you. So then they're so if it does and if you're cool, but your asthma came, and it sounds like an excuse, so I just don't say it. I'm just like, yeah, I lost, whatever."

Media Portrayals. The last subtheme, media portrayals, was discussed only by seventh and eighth graders. They reported that most people with asthma on TV or in movies are portrayed as weak and unable to "do the same things as other people." They also noted that their peers may not view asthma as a severe disease because it is not as publicized as other diseases like diabetes and acquired immunodeficiency syndrome (AIDS). Specifically, I seventh grader noted that you see commercials all the time about other diseases but you never hear about asthma. The lack of information in the media is consistent with the intervention preferences of seventh graders (conducting a school-wide survey on asthma and then presenting information to the whole school) and eighth graders (putting on a play about asthma for the entire school).

Theme 4: Appealing to Youth. A final theme emerged from the data related to interventions that appeal to youth. These findings parallel results from the second survey completed by the focus-group participants. Mode and content preferences collected on this second survey are outlined in Tables 3 and 4.

Across all 3 grade levels, personalization was important, though it differed in important developmental ways. Among the sixth graders, content preferences referenced the self (pictures of self, activities important to self, "my ideas versus other kids' ideas"). The seventh graders focused more on developing a greater awareness of themselves in reference to others (stories of other youth "like how old they are, how fast they run"). The eighth graders referred to personalization as "custom" and were more interested in understanding larger groups or societies. It is notable that among the seventh graders, tailoring made perfect sense.

They could just pick a sport from them to play, and then show how they would use their inhalers or pills or whatever.

You could like put topics on the survey and ask the kids like to check off which ones would be the most important, and then try to put them together into one like.

Tailoring materials based on how they looked also differed across the grade levels. Sixth graders preferred characters with multiple piercing and who were either movie stars or musicians. The seventh graders wanted stories that reflected "girls being bad, boys being good," suggesting an interest in testing gender norms. Eighth graders preferred images that represented diversity (gender, ethnicity, and other observable characteristics). They also thought sports celebrities were important to some people.

Methods to prompt medication use and other management behaviors were identified as important components to include in an intervention for young adolescents with asthma. This included the use of traditional alarm clocks and cell phones to prompt use. Finally, students reported that rewards for successful management were key to achieving change. For sixth graders, this included money, prizes, and candy. Seventh graders identified money and positive feedback from the doctor. Eighth graders indicated candy or positive feedback from asthma devices, such as a ring tone to indicate that the peakflow meter reading was accurate.

# **DISCUSSION**

As a child grows older and expands his or her social network, his or her general and asthma-related behaviors

Table 3 Intervention Design Preferences (n = 28)\*

	% (n)
Modes of intervention delivery	
Video games	85 (23)
Web site	74 (20)
Chat room	56 (15)
Play for elementary school students	48 (13)
Call-in radio show	37 (10)
One-on-one feedback	7 (2)
Television specific	
Video	63 (17)
TV show	56 (15)
Materials/objects	
T-shirt	78 (21)
Stickers	44 (12)
Membership card	41 (11)
Magazine mailed home	37 (10)
Hats	37 (10)
Key chain	37 (10)
Diary	33 (9)
Pens	33 (9)
Booklet with activities	30 (8)
Magnets	26 (7)
Inhaler covers	26 (7)
List of doctors to call or e-mail with questions	22 (6)
Alarm/medication reminder	19 (5)
Fanny pack	15 (4)
Peakflow meter	15 (4)
Daily planner	11 (3)

<sup>\*</sup> Information gathered at post-focus group survey; n = 28; 50% (14) sixth graders, 21% (6) seventh graders, and 29% (8) eighth graders; 64% (18) female; 43% (12) African American.

must be implemented in a greater number of contexts. <sup>2,4,11</sup> The evidence indicates that asthma management interventions for children and adults have been found to be moderately effective at improving asthma-related outcomes, yet few interventions have been designed specifically for young adolescents. <sup>16</sup>

This study sought to identify factors that influence asthma management among young adolescents. Four themes emerged from focus groups with students at 2 middle schools: (1) barriers and contextual influences, (2) developmental issues, (3) illness representations, and (4) appealing to youth. The transition into middle school presented a number of challenges including greater expectations in physical education and a broader and less supportive social network. The positive attributes ascribed to good managers, the negative ones ascribed to poor managers, and the low perceived severity of asthma will inform the development of intervention messages that may appeal to youth. Finally, we determined that tailoring interventions made sense to these youth, particularly when the content related to the self.

Table 4
Intervention Content Preferences\*

	% (n)
How to manage asthma	67 (18)
attacks at school	
Will I outgrow my asthma?	59 (16)
What is asthma?	59 (16)
Sports and asthma	59 (16)
Illicit drugs and asthma	59 (16)
Why people have asthma?	56 (15)
How to manage asthma	52 (14)
attacks at friend's house	
How to stop an asthma attack	52 (14)
How to manage asthma	48 (13)
attacks at home; how to	
avoid triggers	
How to talk to my parents/caregivers	41 (11)
about asthma	
How to talk to teachers and	41 (11)
coaches about asthma	
How to talk to doctors about asthma	38 (10)
What asthma does to the rest of my body	38 (10)
How to talk to friends about asthma	33 (9)
Types of medication	30 (8)
How to get my doctor to talk	26 (7)
to me instead of my parents	
How to use a peakflow meter	19 (5)
Ways to remember medicine	19 (5)
Managing asthma at school	19 (5)

<sup>\*</sup> Information gathered at post-focus group survey; n = 28; 50% (14) sixth graders, 21% (6) seventh graders, and 29% (8) eighth graders; 64% (18) female; 43% (12) African American.

#### **Lessons Learned**

Our study was set in middle schools because of our interest in improving management during this developmental transition. As anticipated, we learned that despite the narrow age range, students in sixth, seventh, and eighth grades may require different intervention strategies and messages to reach and appeal to them. In particular, sixth graders were more concerned about how they were perceived among peers, whereas seventh and eighth graders were more concerned about their future in society.

Second, a school setting offers advantages in accessing youth, offering a credible source to parents during recruitment, and having a place to meet. However, working with schools also presents some challenges, including obtaining informed consent from parents. The low-risk nature of this study allowed us to obtain passive informed consent from parents. This approach also fostered autonomous decision making among the students as they had to self-identify as having asthma, independently sign up to participate in the focus groups, and sign an assent form. With the school nurses' help, we were able to garner interest from more students than we had originally anticipated, and our attendance rates at the focus groups were very good. Research that requires active parental consent should consider the need for autonomy and other developmental changes that are occurring within the target population to best reflect their needs, as well as constraints that may be imposed by the setting.

#### Limitations

We used 2 methods to identify students with asthma: parent-reported school health records and student self-report. Partial validity of the school health records was obtained, as evidenced by the 100% match between those students who self-identified as having asthma and data in the school health records. Despite these efforts, a limitation of this research is the lack of information on students whose parents refused their child's participation (21%) and students who did not sign up to participate (48%). We did not have access to school records to examine differences between these groups of students. Nevertheless, this was a fairly large sample of focus-group participants who met over the course of 7 weeks to gain in-depth information about their asthma care needs.

During the focus groups and administration of the short surveys, we determined that few students understood the difference between controller and rescue medication. Thus, we were unable to differentiate between types of medication during the focus-group discussion. This finding supports the need to provide more information on the purposes of various medications.

#### CONCLUSION

The developmental period between childhood and adolescence can be a difficult period. Numerous social, cognitive, and physiological changes are occurring, combined with the transition from elementary to middle school.¹ This developmental period is generally associated with greater autonomy and independence.² Interventions that capitalize on this transition are more likely to be efficacious and impact other elements of the youth's life. ■

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# **Asthma in Middle Schools:**

# What Students Have To Say About Their Asthma

August 2006 issue of Journal of School Health

# Earn .5 CECH Category I CHES, OH0005 Earn .6 Continuing Nursing Education Contact Hours

- Barriers that students cited for not managing their asthma well included all of the following EXCEPT:
  - a) Students considered managing their asthma annoying.
  - b) Students considered managing their asthma time consuming.
  - Students found it hard to remember to take their medicine with the new demands of middle school.
  - d) Students felt they had outgrown their asthma and didn't need to manage it anymore.
- 2. Students stated that they sometimes failed to report an asthma attack to teachers and/or coaches because:
  - a) Losing class time would negatively impact their grades.
  - b) After asking to leave practice or a game, coaches would not let them return to play.
  - c) Teachers and coaches often accused the student of faking an attack.
  - d) Teachers and coaches treated them differently when they knew the student had asthma.
- 3. The most commonly reported management strategy cited by students for handling an asthma attack was:
  - a) Calling their parents to ask for advice.
  - b) Using their rescue inhaler as soon as they started feeling bad.
  - c) Altering their activity level.
  - d) Checking their peak flow.
- **4.** Sixth-grade students reported increasing problems with managing asthma as they transitioned from elementary to middle school for all of the following reasons **EXCEPT**:
  - a) Multiple teachers.
  - b) Increased requirements in PE.
  - c) Feeling that middle school was very large and teachers weren't concerned about their asthma.
  - d) Teachers felt students should now manage their asthma on their own.
- 5. Of the following modes of intervention delivery, which one had the lowest student approval rating:
  - a) Call-in radio show.
  - b) One-on-one feedback.
  - c) Chat room.
  - d) Video games.

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